Statement of Rita M. Landgraf,
Secretary of the
Delaware Department of Health and Social Services

Before the
Committee on Health, Education, Labor and Pensions
United States Senate

Hearing on
***Olmstead* Enforcement Update: Using the ADA**
to Promote Community Integration

Presented On
June 21, 2012

Statement of Rita M. Landgraf

Before the Committee on Health, Education, Labor and Pensions
United States Senate

Hearing on
***Olmstead* Enforcement Update: Using the ADA**
to Promote Community Integration

June 21, 2012

Mr. Chairman and Members of the Committee, I am honored to testify before you today about the progress being made on advancing community inclusion for individuals with disabilities. My name is Rita Landgraf and I am the Cabinet Secretary for the Delaware Department of Health and Social Services or DHSS. DHSS is the largest state agency, employing over 4,000 individuals in a wide range of public service jobs. Our department includes 12 divisions, which provide services in the areas of public health, social services, substance abuse and mental health, child support, developmental disabilities, long-term care, visual impairment, aging and adults with physical disabilities, and Medicaid and medical assistance. The Department includes four long-term care facilities and the state's only psychiatric hospital, the Delaware Psychiatric Center.

Our Department's mission is to improve the quality of life for Delaware's citizens by promoting good health and well-being, fostering self-sufficiency, and protecting vulnerable populations.

My role in public service was mainly due to my role as a life-long advocate in the areas of disability, health care and senior issues, including as the former executive director of The Arc of Delaware and the National Alliance on Mental Illness in Delaware, and president of AARP Delaware. I am a firm believer in the Supreme Court's Olmstead decision and the Americans with Disabilities Act. In other words, I am a believer that individuals with disabilities have the same rights as all citizens to live in community and it is our responsibility, in the public sector, to provide supports to enable them to exercise that right in a meaningful and purposeful way.

I do not believe, it is enough for us to be in mere compliance with the ADA – Integration Mandate and Olmstead, but we, as state leaders, must embrace the intent of the law beyond the compliance and embed inclusion and the benefits of diversity as a core value. We must engage our partners across the federal, state and local governments, and be inclusive of individuals with disabilities as we develop best practice policy and implementation. This is not merely meeting the objectives of enforcement or a settlement agreement; it is about systemic reform that enables services to meet the desires of the market to live ordinary lives with identified supports. It means embracing and embedding the ADA purpose statement (section 12101 (a) (8)):

> The nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

Our state and federal systems need to ensure that our services adhere to these goals that many of us take for granted.

I. Delaware's Experience with Community Integration of People with Disabilities and the Olmstead Decision

We know that States, CMS, and disability advocates are beginning to evolve to a new understanding of the "Olmstead Community Integration Mandate". The fundamental question is about "how government resources can support a quality of life for people with significant disabilities (eligible for Medicaid funding) that enhances full community participation, independent living and economic self-sufficiency?"

Today, in Delaware, it is a value that we are committed to extending across the state through meaningful systemic reform that promotes integration of individuals with disabilities in our society. Our Governor, Gov. Jack Markell, is committed to this priority, bringing the full weight of his office and the political will to accomplish this restructuring. However, the Delaware system has not evolved dramatically since the passage of ADA in 1990 and

since the 1999 reaffirmation of the Integration Mandate by the Olmstead ruling.

Unfortunately, for decades in Delaware, the state has had an over reliance on facility based care and options within community have been limited to mid to small group living homes. Far too many individuals were placed in institutions and remained there for extended periods. Delaware's institutional bias has been significant. For our state, an AARP survey found that 87 percent of the State's long-term care funds for aging and physical disability services is spent on care at facilities, compared to the national rate of 66 percent. When the developmental disabilities population is included, Delaware does fair better in meeting the national average, but this was a result of litigation action by The Arc against the state in 2002. The 2002 litigation did indeed impact the delivery of services to those with developmental disabilities and enhanced community supports, but did not promote systemic reform across government. Since 2009, under the Markell administration, we have focused on shifting our resources and our delivery strategy to a community first focus. Individuals with disabilities should not have to prove that they are worthy of community. We ask that of no other population cohort and community should be the norm not the exception. The level of reform Delaware is addressing for individuals with serious persistent mental illness is seen, by us, as the proto-type for all with disabilities and the aging population in need of supports. It begins with a simple, but powerful expectation:

Individuals with disabilities can live in their own home, have meaningful employment and be ordinary Delawareans. They may require some level of support, but those supports need to be provided that effectively foster independence and fully engage participation in society. This is the norm for individuals without disabilities.

A pivotal benchmark for Delaware to excel in our commitment to meaningful reform is the July 6, 2011 settlement agreement between the

State and the U.S. Department of Justice which resolved a three-year investigation of the Delaware Psychiatric Center.

More importantly, the agreement became the blueprint for how Delaware would provide mental health services to individuals with severe and persistent mental illness, and creates the prototype for systemic reform across the government, in support of all individuals with disabilities.

II. Creating Systems That Will Make Olmstead a Reality

In order to comply with the agreement, the State must prevent unnecessary institutionalization by offering agreed upon community-based services to the target population. The target population is a subset of individuals with SPMI (serious, persistent mental illness) who are at the highest risk of unnecessary institutionalization. The agreed upon plan requires Delaware to move individuals from Delaware Psychiatric Center (DPC) into the community and for upgraded community supports and services. Our discussions with the USDOJ impressed upon them that we share their vision for improved mental health services in this state. The USDOJ findings made clear what we already knew, what we knew we needed to do and where we were already headed, which was to stop the historical over reliance on institutionalization and moving to more community-integrated and compassionate care. I believe this is an agreement that reflects where we want to take this State. We want to make this state a leader in mental health services, and the USDOJ shares that vision.

The agreement is a multi-year commitment to provide improved mental health services in Delaware. To the USDOJ, it may be about ensuring we're complying with the Americans with Disabilities Act. But to us, it is about providing services to our neighbors, our family members, and our friends who have persistent mental health issues but who can, with the right support, be full participating, thriving members of our communities. More importantly, this agreement is the blueprint for how we are going to provide mental health services to persons with severe and persistent mental illness in this State. It will also set the direction for how we re-tool

our system for all with disabilities. It is an approach based on providing services to people in the community, so that we can achieve better outcomes for persons with mental illness, and we can do so in a manner that protects their independence and sense of community.

III. How the State is Advancing the Reform on the Ground

I now wish to focus on how the state is innovating practices to accelerate building a recovery-based, community-robust system of care. DHSS created a new Request for Proposal (RFP) directed toward facilitating the discharge of individuals who have been institutionalized at DPC, most from six to more than 15 years. The RFP developed a "case rate" for each individual at DPC and these will be bundled into a total amount that will represent that provider's budget for this work. The provider will be expected to provide every service and support required for each of these individuals with the exception of significant physical health care emergencies. This rate is now a comprehensive rate that allows for all inclusive care and will incentivize the provider to support the individual within the least restrictive environment and will provide the funds to enhance the community level of support. The focus of our 5 year plan is:

- Establishment of community based programs and use of DPC as an acute mental health hospital for stabilization as a hospital would be for individuals with a physical health crisis.
- Establishment of Individualized Recovery Plans, inclusive of the individual's dreams
- Expansion of the crisis hotline to 24 -7
- Expansion of Mobile crisis teams that can respond **across the state** within an hour's timeframe
- Development of a new crisis walk-in center in our rural county and crisis stabilization beds throughout the state in typical apartment settings.

- Expanded consumer run drop-in centers.
- Peer-to-peer counseling. The successful implementation of a Peer Support Specialist program at DPC to work with the DPC Recovery Teams and the Community providers to model individualized treatment and recovery planning strategies

- Effective July 1, Medicaid will reimburse for telemedicine services: - this is extremely important in our rural locations, inclusive of
- Consultations, office or outpatient visits.
- Psychotherapy.
- Medication management.
- Psychiatric interview or examination.
- State Rental Assistance Program (SRAP). – Bridge financing via vouchers and connections with typical landlords. Delaware developed the State Rental Assistance Program (SRAP) to serve low-income Delawareans who require affordable housing and supportive services to live safely and independently in the community. At DHSS, we are referring individuals from DPC and from other state-run nursing facilities to the Delaware State Housing Authority for rental housing vouchers. One of the most difficult things for individuals who have been in an institution for a long period is affording a place to live. SRAP provides that necessary foundation in making that transition. DHSS has created a Housing Team made up of individuals from within our disability divisions that are dedicated to becoming housing support experts to continue to assist in supporting individuals locate the housing of their choice as well as working with our State Housing Authority and municipalities to expand the integrated housing for individuals with disabilities.

Given the fiscal challenges, the need for smarter budgeting, smarter spending, and smarter management must take center stage if we are to

achieve meaningful integration. We need to embrace the philosophy of community based living but without the re balancing and flexibility of the funding system, the system will remain vulnerable to stagnation and erosion. Most states have funding aligned with infrastructure, in personnel, buildings that are growing older and in repair, rather than funding the individual based on their individualized plan and integrating with the natural environment. Inclusion allows for leveraging of resources both paid and natural. So we can leverage our existing resources both fiscal and human with a focus on community. We are shifting resources out of the facilities and promoting a community based system of support. DHSS is focused on the development of a quality assurance program that incentivizes based on outcomes as they relate to the promises of Olmstead/ADA and not funds for volume. If we evaluate based on the ADA and individuals achievements, we are placing a monetary value on the ADA principle. Some refer to this as re-balancing or re-tooling, regardless of the term, it is an effort to resource the community and leverage both funding and resources throughout and across the government.

In addition to the operational implementation of Olmstead and ADA, the Department is engaging in a state public policy review. We have a rather antiquated law relative to detainment and commitment which has led to over 3,000 yearly involuntary commitments. That amounts to approximately 8 involuntary commitments per day. The state has in the past funded the involuntary commitments but did not fund voluntary commitments. We are working towards revamping the detainment law and will require a new credentialed mental health screener, who will be an expert in community based options and work closely with the emergency doctors, psychiatrists, and others to divert individuals to the most appropriate care level. DHSS is advocating changing how emergency evaluations are conducted, preventing unnecessary encounters with law enforcement and avoiding needless trips to emergency rooms and psychiatric hospitals. Individuals will be encouraged to voluntarily commit, if indeed this is seen as the most appropriate level of care and the state will fund both voluntary and involuntary commitments. A past state practice was to fund only involuntary commitments and many individuals were not even provided an opportunity

to voluntary commit to treatment, which is a huge infraction on their rights and presents a barrier to empowerment. The effort to re-vamp this law has not come without objections from the trial lawyers and a protection and advocacy attorney, since, as a compromise, an immunity clause is in the draft legislation for emergency doctors, psychiatrists and credentialed mental health screeners. It is hard to predict if this policy change will be successful since it has strong lobbyists on both sides of the argument. However, Bryce Hewlett, Executive Director of the Delaware Consumers in Recovery Coalition has stated "any loss of civil rights for any amount of time is unacceptable, but we've decided to support this bill because it takes so many steps in the right direction."

Meaningful reform must evaluate both operational and policy practices must be encompassing across the system, inclusive of the entities that support the typical population and develop procedures that encompass reasonable accommodations beyond structural, tangible accommodations. We need to evaluate accommodations for the class as well as for each individual, to assure equality of opportunity, full participation, independent living and economic self-sufficiency.

IV. A Model for Statewide Reform

As a State, we are committed to making the mandate of ADA and Olmstead a reality. As a State, we are not only focused on supporting individuals moving out of DPC and into the community, but are actively accessing all within our state facilities and asking if they want to return to their community and are assisting them to do so. DHSS is working with an independent agency to perform this assessment and providing education to the residents on ADA and Olmstead. We also continue to assist individuals in their desire to move from institutional settings to the community under the Medicaid Money Follows the Person program and our Journeys program. In addition we are working with hospitals and have created a diversion team that provides support to any entity that is evaluating a long term care need. Our goal is a community first approach to care and returning individuals to their home environments or providing supports within the least restrictive environment. This recently developed service is

the Care Transitions Program, and falls under the umbrella of the Delaware Aging and Disability Resource Center (ADRC). The program extends community living for individuals who are in the community or in the hospital and are seeking admission to one of the state long term care facilities.

The goal of the Care Transitions Program is to 1) extend community living for individuals who are at high risk for nursing home placement by mitigating immediate risks and stressors that are prompting a move to a nursing home; 2) create a flexible spending pool to facilitate access to services and products. We initiated the diversion teams in February of 2011 and since that time, 86% of those referred to facility based care have been diverted back into the community with appropriate supports. It is anticipated that this percentage with increase as we evaluate those situations that were not able to be diverted and initiate a community based structure to address these issues, especially if we find they are common across the population requiring facility based care.

The Money Follows the Person Demonstration (MFP) "Finding A Way Home" Program, is a special project funded by the Federal Government and the Delaware Department of Health and Social Services (DHSS) Division of Medicaid and Medical Assistance (DMMA). The MFP Program is available to assist eligible individuals that choose to participate in moving from an eligible Long Term Care (LTC) facility, (nursing home, Intermediate Care Facility for Developmental Disabilities ICF/DD) to an eligible residence in the community with available community services and supports.

The Nursing Home Transition Program is a state-funded and the overall goal of the program is to identify, inform and assist nursing home residents, who are not Medicaid-eligible, who want to move to a community-based setting. The program offers individualized case management to accomplish this goal. To date, both of these programs have supported 177 individuals in facility based care back into their community. Currently, there are 58 individuals awaiting transition from facility care within the Money Follows the Person program. Currently MFP does not pay for home modifications until a participant is discharged home. This leaves people in a potentially

unsafe situation if they cannot get in and out of the home without a ramp or other modifications. This also socially isolates people as they cannot leave their home for church, shopping, employment or other community outings.

In our Medicaid program, we are changing the manner in which we deliver services to our long-term care population and those eligible for both Medicaid. Individuals in need of long-term care services require the greatest level of care and, therefore, are the most costly to serve. On April 1, 2012, we began utilizing an integrated long-term care approach that enhances and builds community supports and options, fully develops a continuum of available services, and so better contains cost while providing the market with what they desire. More importantly, it will more effectively support participants' desire to remain in the community. As the leader in the department, I have a standing monthly meeting with our Managed Care Providers and the Medicaid leadership to ensure that the purpose of the program is to develop enhanced community options and not merely for cost containment. I continue to outreach to the advocacy and consumer organizations to ensure that the program is indeed creating a community based system of support and wish to ensure this is successful for those who access the system.

In the area of substance abuse, mental health, disability and aging, we know that the market is in need of service and support enhancements that promote community-based care. We are also working on measures that would divert individuals from prematurely entering facility-based care through a more comprehensive universal effort in effective discharge planning, practice and the creation of state diversion teams that work with hospitals, Adult Protective Services and others who have a need for support but may not require a 24-hour residential setting. These situations typically led to an automatic referral to a facility without evaluating community based support planning and engaging the state at time of an admission.

In addition, we are working with St. Francis Healthcare, which will open Delaware's first PACE site in fall 2012. This Program for All-Inclusive Care for the Elderly provides site-based comprehensive, coordinated long-term services and supports to Medicaid and Medicare participants who are 55 and older, require a nursing home level of care and are able to live safely in the community. This model of care can be replicated for individuals with disabilities.

The State and the USDOJ also know that for individuals with serious, persistent mental illness, many have found themselves interacting with the criminal justice system. The state has created an across the cabinet approach to support those existing the criminal justice system and providing the support network six months prior to any release. Known as the I-Adapt (Individual Assessment and Discharge Planning Team) Coalition consists of the Departments of Correction, Health and Social Services, Labor, Education and the State Housing Authority. The purpose of the I-ADAPT teams is to coordinate local efforts to support individuals exiting the Delaware Correction system and to develop relationships between service providers and government and build sustainable community supports and buy in for the State's reentry efforts.

V. Fiscal Security and Empowerment

Up until now, the focus of ADA/Olmstead has primarily been on expanding housing options (home, apartments, and independent living options with necessary supports). However, underlying support for full community participation must be a focus on financial capability and advancing "economic self-sufficiency". Without attacking the underlying issue of poverty, quality of life choices are diminished. We know poverty impacts adversely mental and physical health, limits community participation, and affects adversely self-concept and others' perception of one's status and value. The next generation of innovation has begun in Delaware and also is being initiated in cities such as San Francisco and New York City. It is the design and implementation of financial empowerment strategies embedded in social and human service delivery.

The Olmstead Community Integration Mandate compels us to attack poverty and financial instability through financial coaching as part of an

individual's Medicaid support plan. Providing financial education and counseling that explores new options for employment (income production), savings (income preservation), and safeguarding and building assets can give our most vulnerable citizens with disabilities hope and goals that will enhance "fuller community participation".

There is no roadmap out of poverty. However, state Medicaid rebalancing of resources to meet Olmstead requirements can use a new lens to design individualized supports for working age adults with significant disabilities. CMS recognizes that community participation must include pathways to advance economic self-sufficiency. Financial coaching and financial empowerment can stabilize individuals and families and raise expectations and results about quality of life experience.

In Delaware, we will use our government infrastructure (Medicaid, Vocational Rehabilitation, Education, Social Services, and Labor) to reset the focus to change thinking and behavior about financial capability through an integrated system of supports that enhance financial empowerment skills and outcomes. We are calling this the $tand By Me initiative: a partnership between DHSS and the United Way of Delaware. The National Disability Institute is working on site in Delaware to integrate financial empowerment as part of our collective service delivery system.

What separates people with disabilities from the rest of the population is financial security. The majority of individuals with disabilities are of extremely low income which further disenfranchises and disempowers the population.

Traditionally, state programs have provided support for basic needs and emergency services for low-income residents. In recent years, a shift in national perspective has moved leadership in major American cities and the federal government to pursue strategies which promote self-sufficiency. By providing low-income Delawareans with the tools and support they need to take charge of their financial lives, the cyclical dependence on benefits will be reduced, which will reduce investments for benefit programs for the state and the negative sense of self created by dependence for the clients.

VI. Need for an ADA/Olmstead Outreach Campaign

I believe we need ADA/Olmstead ambassadors throughout the states to promote the premise behind the civil rights movement and institute a broad education campaign. States must incorporate this awareness throughout the delivery system and in all areas of the Cabinet to fully support the civil rights of individuals with disabilities as a core value.

Delaware's Court Monitor, Dr. Robert Bernstein noted the following in his first 6 month report to the Court:

"The federal laws that are its basis have been around for far longer than the settlement agreement; the ADA was enacted over twenty years ago, and the *Olmstead* decision was rendered over a dozen years ago. Despite the fact that these federal laws have enormous implications for people with SPMI and for how public mental healthcare is delivered, and notwithstanding numerous trainings by the state over the years, the Monitor found a widespread lack of knowledge about the principles of the ADA, their crucial implications for people with SPMI, and how they relate to public services. Senior staff members have an understanding of the Settlement Agreement and underlying civil rights laws. However, just a step or two below leadership positions, it is apparent that there is often only a passing familiarity with the ADA, the Settlement Agreement, and their requirements. This is particularly significant because it is in these settings, rather than in the offices of management, that decisions about services and interventions for specific individuals are made. Perhaps most poignant is that interactions the Monitor has had with consumers suggest that they are unaware of their own civil rights under the ADA, let alone the fact that the State has effected an agreement with DOJ.

It is obvious that individuals who are charged with implementing the Settlement Agreement and those who are intended beneficiaries should be well versed in its requirements. It is also important that for the Settlement Agreement to represent something beyond a laundry list of prescribed actions, stakeholders need an appreciation of the underlying values. It is the Monitor's impression that a lack of basic knowledge about the ADA and *Olmstead* has sustained providers, courts and others in unquestioningly making decisions that perpetuate segregation, undermine self-sufficiency, and even result in coercive practices. "

In closing, permit me to share with you my early lesson on inclusion:

My path here today began when I was 12 years old, when a young neighbor Mike who had an intellectual disability, ventured out into our community to befriend us. What Mike wanted was to be included with his peers and be a part of our group. What he encountered was ridicule at his expense. The memory still weighs heavy on my mind and heart. I didn't tease Mike, but I did nothing to stop the others. That haunting look on Mike's face changed my life forever, and I committed myself to working towards a system that educates and promotes diversity and inclusion. Mike on the red bike taught me my first lesson on the value of inclusion. I saw Mike a few years back and he told me that he now drives a car, works at a farmers market and is married. He is an ordinary Delawarean, a full participating community member and was smiling broadly. I told him that he was also a great teacher.

Thank you for this opportunity to testify and I look forward to your questions.

Acknowledgements:

Robert Bernstein, Ph.D., President and Executive Director, Judge David Bazelon Center for Mental Health Law

Jennifer Mathis, Deputy Legal Director, Judge David Bazelon Center for Mental Health Law

Michael Morris, Executive Director, National Disability Institute

Johnette Hartnett, Ed.D. Director Strategic Partnerships & Research, National Disability Institute